

**UNDERSTANDING BARRIERS THAT PREVENT THE ACCURATE COLLECTION OF
RACE AND ETHNICITY DATA**
Rhode Island Childhood Lead Poisoning Prevention Program
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BACKGROUND

The collection of race and ethnicity data is an important part of public health. These data allow us to monitor disease trends, track health status and assess progress in improving health among various population groups. Additionally, these data help us to assure non-discriminatory health care access and treatment, identify issues surrounding access to care and discrimination, and track the extent to which members of minority groups are beneficiaries of and participants in federally assisted programs. Given the importance of these data, state and local governments must adhere to a set of compliance guidelines to maintain, collect, and present data on race and ethnicity.

In 1988, The Rhode Island Department of Health's First Policy Guide was assembled for collecting race and ethnicity data. The Guide was designed to evaluate and monitor the accessibility of care for minorities in Rhode Island and provided instructions for the collection of race and ethnicity data in a consistent manner. In 1997, the Federal Office of Management and Budget's Statistical Directive 15 (OMB Directive 15) developed new guidelines with which all state governments were required to comply. In 1998, the Rhode Island Department of Health, along with the Minority Health Advisory Committee (MHAC) and the Data Subcommittee, began to develop a new guide for collecting race and ethnicity data in accordance with the 1997 OMB Directive 15 standards. The current Policy for Maintaining, Collecting, and Presenting Data on Race and Ethnicity (July 2000) for the Rhode Island Department of Health can be located on the Rhode Island Department Health website at <http://www.health.ri.gov/chic/minority/index.php>. The minimum standards for the collection of race and ethnicity data are as follows¹:

Ethnicity:

- ☐ Hispanic/Latino
- ☐ Not Hispanic or Latino

Race:

Please check one or more

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African-American
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White

The ethnicity question must always be placed first, and individuals must be given the option to check more than one race. An "other" category may also be included in the race question for more detailed data collection.

¹ Policy for Maintaining, Collecting, and Presenting Data on Race and Ethnicity. Rhode Island Department of Health, Office of Minority Health and Office of Health Statistics. July 2000.

OBJECTIVES

Although all data collection systems at the Rhode Island Department of Health are required to collect race and ethnicity information according to the standards outlined in the Policy for Maintaining, Collecting, and Presenting Data on Race and Ethnicity (July 2000), the data that are collected are not always complete and accurate. The Rhode Island Department of Health's Childhood Lead Poisoning Prevention Program (RI CLPPP) is one program that is faced with the challenge of incomplete race and ethnicity data. Race and ethnicity information are required to be collected on the lab slip when a child has blood drawn for a blood lead test. Approximately 65% of ethnicity data and 40% of race data are missing each year from blood lead test results reported to RI CLPPP. In response to this gap in data collection, the RI CLPPP conducted a pilot survey in the fall of 2004 to gain a better understanding of the barriers that prevent race and ethnicity data from being collected in the laboratory setting.

The objectives of the pilot survey were:

- To identify barriers that prevent laboratory professionals from asking race and ethnicity questions;
- To assess how comfortable people are reporting race and ethnicity for themselves, as well as for their children.

METHODS

Data were gathered by surveying three groups of people: laboratory professionals, parents with children younger than 12 years of age, and adults without children younger than 12 years of age. The survey was administered by the parent consultant for the Rhode Island Childhood Lead Poisoning Prevention Program who visited a total of 20 laboratories across the state, and spent approximately one hour in each laboratory site. A complete list of participating laboratories is included in Appendix # 1. (For the purposes of the survey, the categories used on laboratory requisition forms for blood lead data were used.) These include:

Ethnicity

- ☐ Unknown
- ☐ Hispanic/Latino
- ☐ Portuguese
- ☐ None of the above _____

Race: (check all that apply)

- ☐ Unknown/Refused
- ☐ White
- ☐ Black or African-American
- ☐ American Indian (including South and Central America)
- ☐ Native Hawaiian/Pacific Islander
- ☐ Laotian
- ☐ Cambodian
- ☐ Hmong
- ☐ Other Asian
- ☐ Other _____

The parent consultant distributed surveys to the laboratory technicians present in the office on the day of the visit, and solicited participation from patients while they were waiting to be seen by a technician. The RI CLPPP received permission from laboratory management at all sites prior to visiting any of the laboratories. Patients that agreed to participate were given the choice to complete the survey in written form or to complete it through a verbal interview with the parent consultant.

The first type of survey was distributed to laboratory technicians who are responsible for collecting race and ethnicity data at the time of a blood draw. The purpose of the survey was to investigate barriers that prevent laboratory technicians from collecting this information regularly. Questions asked included:

- When completing paperwork for patients, how often do you fill out race and ethnicity questions?
- How do you determine the race and ethnicity of the patient?
- What are some of the reasons that prevent you from filling out these questions?
- Are you interested in receiving training about how to collect race and ethnicity information?
- Would it be easier to complete the race and ethnicity questions if the patient filled out the answers on the form rather than you asking the questions?

The complete laboratory technician survey that was utilized is included in Appendix # 2.

The second type of survey was distributed to parents with children younger than 12 years of age. The purpose of this survey was to identify how parents felt answering race and ethnicity questions about their child and what would make them most comfortable answering these type of questions about their child. Questions asked included:

- Have you taken your child(ren) to a laboratory in the last six months? If yes, did your laboratory professional ask you about your child's race and ethnicity?
- How comfortable are you answering questions about your child's race and ethnicity?
- Please describe anything else that may make it more comfortable to report the race and ethnicity of your child.

The complete parent survey that was utilized is included in Appendix # 3.

The final type of survey was distributed to adults who did not have children less than 12 years of age. This survey was used to identify the comfort level of patients answering a question concerning their own race and ethnicity and to identify what could help to make them more comfortable answering these questions. Questions asked included:

- Have you been to a laboratory in the last six months? If yes, did your laboratory professional ask you about your race and ethnicity?
- How comfortable are you having a doctor or laboratory professional ask you about your race and ethnicity?
- How would you like questions about your race and ethnicity to be asked? Would you like to be asked directly, complete a form, or some other means?

The complete general public survey that was utilized is included in Appendix # 4.

RESULTS AND BARRIERS DETECTED

A total of 138 surveys were completed. Forty-seven laboratory technicians, 42 parents, and 49 adults without children under the age of 12 completed the surveys. There were a total of 7 incomplete surveys and 40 patients that refused to participate. Laboratory technicians and patients who participated in the survey ranged from 20 to 60 years of

age, lived in various towns throughout Rhode Island, and represented a wide variety of ethnic and racial categories that they self-identified including: Hispanic, Italian, Jewish, African American, Anglo Saxon, Portuguese, American Indian, Laotian, Cambodian, Native American, Native Hawaiian or Pacific Islander, White, Black, and Hmong.

Results: Laboratory Professionals

Forty-seven laboratory professionals completed the survey. Of the 47 people surveyed, 35 (74%) of them said that they rarely or never complete the race and ethnicity questions on their client's lab paperwork. When they do complete the race and ethnicity questions, laboratory professionals most often ask the patients directly to identify their own race and ethnicity, or they ask the patients to complete the form themselves. Occasionally, laboratory professionals guess the race and ethnicity of their patients based on their patient's name and/or appearance.

Two common reasons laboratory professionals reported not asking the race and ethnicity questions were because they were uncomfortable asking (60%) and because of a language barrier (10%). Laboratory professionals reported that they did not want to make patients feel uncomfortable or think they were being discriminated against by asking this information. Fifteen percent of the laboratory professionals responded that it was not their responsibility to fill out this information, or that data fields to collect race and ethnicity are not in the computer system. Oftentimes patients bring the laboratory slip completed by their doctor when entering the laboratory registration area, at which time it would be the responsibility of the front desk personnel to ask the patients race and ethnicity questions. Ten percent of the laboratory professionals reported finding the data useless or unnecessary.

More than half of the laboratory professionals reported that it would be easier to collect race and ethnicity information if the patients filled out the form themselves, or if the patients were shown a numbered list of race and ethnicity categories and then asked which number best described him or her. Only 8 (17%) out of the 47 people surveyed were interested in receiving training about how to collect race and ethnicity information in a culturally sensitive way.

Results: Patients (with and without children under the age of 12)

The results of the survey demonstrate that the majority of the patients felt comfortable answering questions concerning race and ethnicity but they may not always answer these questions truthfully. Of the patients who had visited a laboratory in the past six months, only 12% of parents (5/17) and 4% of adults without children under age 12 (2/40) had been asked about race and ethnicity. Thirty-nine (93%) of the parents surveyed reported feeling comfortable or very comfortable reporting the race and ethnicity of their children and forty-six (94%) of the adults without children under age 12 reported feeling comfortable or very comfortable when a doctor or laboratory professional asks about race and ethnicity.

Quote from a patient regarding race and ethnicity:
"I really don't have a problem being asked about either."

Thirty-six (86%) parents and forty-three (88%) adults without children under age 12 stated that when asked about race and ethnicity they answer truthfully. Twenty (48%) of

the parents surveyed reported that they would prefer to be asked directly to state their race and ethnicity, while another 20 (48%) reported that they would prefer to fill out the form themselves. Twenty-five (52%) of the adults without children under age 12 reported that they would prefer to be asked directly to state their race and ethnicity, while 19 (39%) reported that they would prefer to fill out the form themselves.

LESSONS LEARNED

The RI CLPPP's parent consultant detected a number of barriers to the reporting of race and ethnicity during the implementation of the survey. For example, when laboratory technicians were asked how they determine the race and ethnicity of a patient some stated that there was no need to ask the patient their race and ethnicity information if it can be determined by the appearance of the patient. Other lab technicians reported that they did not know that the information was required to be documented for all blood lead tests. Furthermore, it became apparent that laboratory technicians and patients had a lack of understanding of the definitions of and differences between race and ethnicity. Many survey respondents were not aware that race and ethnicity are categorized separately. Patients completing the survey expressed interest in learning the purpose for collecting the information and how the information would be used. Few patients expressed that they did not want to provide the information because of confidentiality, because they did not want to be categorized, and/or because they did not want to be discriminated against by the laboratory technicians. The patients mentioned that the collection of such social categorizations has no biological significance unless otherwise used for medical research.

Quote from a patient:

"If my child was being tested for sickle cell, than obviously race is a factor. But when the question is asked where it has no purpose, this annoys me."

Although only 17% of laboratory technicians stated that they were willing to participate in a training on the collection of race and ethnicity data, most stated they were willing to give patients educational materials explaining the purpose for collecting race and ethnicity information.

RECOMMENDATIONS

It is clear from the results of this survey that improvements are needed regarding the collection of race and ethnicity data.

The general findings of the survey indicated that laboratory professionals are uncomfortable asking patients about their race and ethnicity, while patients are comfortable reporting race and ethnicity information. Patients also indicated that they are comfortable filling out the form themselves, or being asked directly about their race and ethnicity. One way to gather the information from patients without making laboratory professionals uncomfortable would be to have patients complete the race and ethnicity questions themselves. Some general recommendations that arose from the surveys include:

- **MANAGEMENT SUPPORT:** Management should support the collection of these data, encourage staff to address the collection of these data, and advise that race and ethnicity data be collected as a part of the up-front paperwork.

- **STAFF TRAINING:** Laboratory technicians are hesitant about asking patients for their race and ethnicity because of the sensitive nature of the questions, and because they feel that it is an “irrelevant” issue. Some stated feeling uncertain about who is responsible for collecting the information. Education is key to the successfully collecting and reporting race and ethnicity data. Race and ethnicity data collection and reporting trainings should be included in the training programs of all new and existing staff.
- **EDUCATING PATIENTS:** A verbal and/or written explanation should be provided to patients that explains why laboratories are collecting this information and how it will be used. When collecting the information, the patient should be notified that the information will remain confidential.
- **PARENTS:** A verbal and/or written explanation should be provided to parents to explain why laboratories are collecting this information about their child and how it will be used. When collecting the information the parent should be notified that the information will remain confidential.

NEXT STEPS

The Rhode Island Childhood Lead Poisoning Prevention Program will be taking the following actions to respond to the findings of the surveys:

- Share the findings of the survey with the Office of Minority Health and laboratories throughout the state;
- Develop educational resources to explain the importance of collecting race and ethnicity data and distribute these materials to laboratory staff;
- Develop educational resources to explain to the public how race and ethnicity data are used and why laboratories collect this information;
- Identify partnerships to conduct larger scale efforts around laboratory data collection methods.